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joint improvement team



The Dementia Services
Development Centre



Telecare and dementia

Using telecare effectively in the support of people with dementia

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Editorial team

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Research and knowledge in the field of dementia care is constantly changing. As new information emerges, changes in how we support people with dementia become necessary. The authors and the publishers have, as far as possible, taken care to ensure that the information given in this text is accurate and up to date at the time of publication. However, readers are strongly advised to confirm that the information complies with current legislation and standards of practice.

Copies of this document are available in alternative formats on request by contacting the Dementia Services Development Centre at the address above.

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Preface

This book explores how telecare can contribute to the support, protection, and quality of life of people with dementia. It also considers the importance of telecare in providing support and reassurance to carers.

This is one of a number of publications funded by the Scottish Government's National Telecare Development Programme¹, in pursuit of the strategic goal of raising awareness of the importance of telecare in contemporary health and social care services. The other books in this series are:

- Telecare and learning disability – using telecare effectively in the support of people with learning disabilities
- Telecare and physical disability – using telecare effectively in the support of people with severe physical disabilities and long-term chronic conditions
- Telecare and sensory impairment – using telecare effectively in the support of people with sensory impairments

The books are written for assessors, care and support staff and their managers, telecare service managers and development staff. Senior managers should also find them useful in informing service planning, and they should help raise awareness, expectations and generally advance understanding among service users and carers.

Each book also contains case studies and a training programme designed to help trainers when designing both awareness-raising and skill-development programmes. Programme directors responsible for basic and post-basic programmes for nurses, housing staff, social workers or occupational therapists should consider these as a sound basis for a module on telecare.

Examples of equipment which might contribute to the safety and quality of life of the person utilising telecare are featured in each book. The aim is to support readers by providing information on some of the wide range of telecare products available. The books do not endorse any specific product or supplier, but provide examples of what is currently commercially available or emerging on to the market. Where possible, details of suppliers/manufacturers have been provided at the end of each book.

As we grow older and take on caring responsibilities or become disabled, technology can help us maintain our independence and quality of life.

1: Introduction

We all rely increasingly on technology in almost every aspect of our lives. Within our homes, devices such as microwaves, DVD players and flat screen TVs enhance the quality of our lives and reduce the amount of time we spend on the drudgery of housework. We rely on computers and mobile phones for information, social contact and entertainment, and to help us make informed choices about purchases and services. Away from home, technology such as GPS (global positioning systems) and satnav (satellite navigation) – often incorporated into our mobile phones – has the potential to guide us, keep us in touch, and keep us safe.

People with dementia ought to have the same access to, and benefits from, this increasingly cheap and accessible technology. As we grow older and take on caring responsibilities or become disabled, technology can help us maintain our independence and quality of life. It can also overcome some of the limitations of specific conditions. One purpose of this book is to raise awareness of these issues and provide practical guidance on how to introduce technology to potential service users.

Demographic change, and the key social policy agenda of shifting the balance of care from institutions to care at home in the community², also requires us to maximise the benefits of technology. There is now plenty of evidence to show that telecare can release significant resources from within health and social care systems and facilitate changes in the balance of care³. It also has the potential to improve important outcomes such as independence and feelings of safety.

This book will outline how telecare can contribute to improved outcomes for service users. It includes sections on:

- definitions of telecare (along with the related concepts of telehealth, assistive technology, environmental controls, and telehealthcare)
- the importance of good needs and risk assessment if telecare is to help meet those needs and manage those risks
- ethical dilemmas and how these can be resolved
- how needs may be met using telecare as part of a package of care and support
- issues particular to carers
- case studies and an outline training programme

Definitions: what is telecare?

In this book the term telecare is used to describe the use of equipment within and outwith the home to monitor changing needs and risks, and to provide alerts and information that enable improved and informed responses to those needs and risks.

Demographic change, and the key social policy agenda of shifting the balance of care from institutions to care at home in the community, requires us to maximise the benefits of technology.

The definition below is the one used in the National Telecare Development Programme in Scotland. It forms part of the 'shared vocabulary'⁴ agreed and published by the Scottish Government, and is consistent with definitions used in the English and Welsh development programmes.

There is a wide range of telecare equipment, and the scope and sophistication of applications has developed considerably over the last 25 years.

Telecare is the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology (ICT) to trigger human responses, or shut down equipment to prevent hazards.

First, second and third generation telecare

There is a wide range of telecare equipment, and the scope and sophistication of applications has developed considerably over the last 25 years. The following informal classification, based on 'generations', provides a way of distinguishing between different stages of development and application.

First generation telecare refers to equipment that forms part of most community alarm services. It is used to describe user-activated alarm calls (by push button, pendant or pull cord) to a control centre where a call handler can organise a response of some kind. This is usually via a neighbour, relative or friend acting as a 'key-holder'.

Second generation telecare evolved from the introduction into basic community alarm services of sensors such as smoke, gas, heat and flood detectors. Second generation telecare now includes sensors which can monitor not just the home environment, but aspects of lifestyle, physiological measures and vital signs. These sensors can collect and continuously transmit information such as when doors are opened, whether taps are running and the use of electrical appliances. Through passive infrared sensors (known as PIRs), movement both within and outwith the home can be detected. This provides much more sophisticated and comprehensive support for managing risk and improving quality of life. Second generation telecare can also be used to provide data about someone's lifestyle, movements and routines, which can be used for needs assessments.

Third generation telecare developed from improved and increased availability of broadband, wireless and audio-visual technology. It offers the potential for virtual or tele-consultations between the service user and their doctor, nurse or support worker, thus reducing the need for home visits or hospital appointments. Furthermore, it provides increased opportunities for people (particularly those unable to leave their homes alone) to 'visit' libraries, shops and maintain contact with family and friends.⁵

Telehealth

In this book the term telehealth refers to the use of monitoring and measuring devices to collect information about vital signs (such as temperature, blood pressure and blood sugar level), symptoms or health conditions in the patient's

home. This information can then be transmitted from the device to a call handler, nurse, or other clinician, who can then advise the patient by phone, text or email on how to manage their symptoms and condition. Clinicians can be alerted to significant changes in a patient's condition, and the patient advised or reassured appropriately. This can take place without the need for a home visit, visit to a surgery, or other consultation. Telehealth is often used to enable people to manage chronic conditions, for example high blood pressure or diabetes.

Telehealthcare

The Scottish Government has published a paper on long-term conditions⁶ which includes a definition of telehealthcare, illustrating how this term emphasises a holistic approach to the person, who should be at the centre of the service:

There is increasing convergence between telehealth and telecare, with the introduction and expansion of remote monitoring as part of the 'telehealthcare' package available in a person's home. Telehealthcare offers a range of care options remotely via phones, mobiles, broadband and videoconferencing. It can improve the patient's experience of care by reducing the need for travel to major cities and hospitals to receive care and treatment. It has been used successfully to provide treatment for dermatological, cardiac and neurological conditions. It enables care to be delivered in remote communities, allows GPs to consult specialists remotely to avoid unnecessary referrals and enables networks of learning for clinicians and maximisation of skill mix for teams.

Assistive technology

Assistive technology is another collective term for devices for personal use designed to enhance the physical, sensory, and cognitive abilities of people with disabilities to help them function more independently.

Environmental controls

Environmental controls are equipment systems that enable people with higher levels of physical impairment or chronic health problems to control access to their home, to summon emergency help and to operate domestic appliances. For instance, a single remote control unit can enable a wheelchair user to control temperature and open and close windows, curtains and doors (in addition to the more conventional functions of controlling TVs, DVD players, and audio equipment).

Telecare as part of a personalised service

Telecare should not be seen as the *solution*, a single one-dimensional response to needs or risk. It is not an alternative to direct care by carers, although it can reduce the need for check visits, 'supervision', or visits to clinics (such scenarios will be explored later in this book). Telecare is effective when it forms part of a personalised programme or package of care and support, and is accepted as such by the service user, their informal carers and other staff/services.

Telecare is not an alternative to direct care by carers, although it can reduce the need for check visits, 'supervision', or visits to clinics.

To be effective telecare requires:

- informed, skilled and personalised outcomes-focused assessment of needs and risk
- resolution of ethical dilemmas around capacity, informed consent and choice (for each individual in each situation)
- training and education for the service user, carers, personal care and support staff in how the equipment can be used or misused and how it should be tested and maintained (for example, battery replacement)

Telecare services

So far, this introduction has only discussed equipment. The term 'telecare services' sets the delivery of equipment in the wider context of health and social care services. In a practical sense, this means efficient, up-to-date monitoring or call centres with trained staff who have access to personal health and social care data and response protocols. These staff will be available every day of the year, and will be skilled in making judgements about the information and alerts sent by the equipment, and in facilitating the most appropriate response possible. Such centres are absolutely essential to the effective use of most telecare equipment. While different agencies may organise their call handling or monitoring staff in different ways, the presence of someone who can interpret the information, provide reassurance, follow detailed individual protocols, and understand the basics of how equipment works is essential to ensuring the maximum benefit to the service user.

Appropriate response arrangements must also be in place, incorporating individualised response protocols which ensure the best possible response to the immediate need or situation. Traditionally this has relied on 'key-holders' – relatives or neighbours who, when contacted by the call centre, would call on the service user and solve the problem or contact services as necessary. Increasingly, in response to higher levels of dependence and more complex needs, agencies are deploying teams of trained carers, who can respond to an emergency and provide personal care, reassurance, or contact other emergency services as necessary.

In order for telecare services to have maximum impact on wider policy goals such as changing the balance of care, they need to be conceived as part of, and located within, local health and social care strategies for different client and patient groups. Service planners need to articulate how telecare developments will enhance home care and housing support services not as an 'add-on', but as an integral part of health and social care service options.

Risk and reliability

No equipment can be 100 per cent reliable forever, in the same way that no 'human' service is completely and consistently reliable. Equipment will come with a manufacturer's guarantee, but in the event of a fault an engineer will need to be called out, and there may therefore be gaps in service provision, even when monitoring is required '24/7'. Equipment which relies on mobile phone signals, internet access or landlines to transmit information will, on occasion, experience the lapses in service that affect these systems. To counter these risks, telecare services need to include backup, testing and business

To be effective, telecare requires an informed, skilled and personalised outcomes-focused assessment of needs and risk.

continuity arrangements (although of course equipment purchased privately will not have these safeguards as standard).

'Interoperability' is a significant issue. This refers to the problems that arise when equipment developed by one manufacturer does not work with the call handling or monitoring system which is already in place, and which was made by another company. Progress has been made in resolving this issue, partly due to the introduction of a new (voluntary) British Standard⁷. However, interoperability remains a problem, especially when equipment does not comply with this standard.

It is very important that these issues are taken into account when care packages are being put together through the use of proper risk assessments and appropriate risk management arrangements.

Access and availability

This book includes examples of equipment that has the potential to contribute to the safety and quality of life of people in need. The examples have not been selected to promote the products of any particular company, but instead to raise awareness of what can be done and what is (or will soon be) available. Where a product is featured, details of the company that sells or manufactures it have been included (see page 34).

Companies specialising in telecare equipment are increasingly able to personalise their products to meet the needs of individual users. Furthermore, they recognise the importance of developing new applications from this starting point. Manufacturers would argue – with some justification – that the scope of what telecare equipment can do is limited by our imagination, rather than by the technology. The cost of equipment is falling, and public bodies now have procurement arrangements in place which should further reduce this cost. In addition, companies welcome contact with service users and professionals to help them understand needs which might be met through new applications.

Some telehealth equipment – blood pressure monitors, for example – can be bought on the high street, and this is a trend that is likely to increase as expectations and understanding of the potential of telecare increases. However, an important part of a telecare service is the response. There needs to be some way in which the information or alert generated by the equipment can be transmitted to someone with the skills and technology to generate a fast and appropriate response.

The major providers of telecare services are local authorities – increasingly in partnership with health authorities. Purchasing budgets are (or should be) available to enable practitioners to access equipment as part of a care and support package. Alternatively, service users should be able to purchase equipment using their individual budgets, or direct payments. In recent years budgets have been enhanced by government telecare support grants, and although some of these schemes may now be coming to an end, health and social care partnerships will continue to explore means of transferring resources so that telecare can develop further using the savings generated.

One consequence of the development in telecare services over recent years is that many authorities have recruited telecare coordinators, or have designated telecare 'champions' within local services. These staff can advise on availability and access, and should find these books helpful in their task of promoting the use of telecare among different client and patient groups.

Telecare equipment needs to be complemented by up-to-date monitoring or call centres with trained staff who have access to personal health and social care data and response protocols.

2: Assessment

An effective and efficient outcomes-focused needs assessment is essential if the potential of telecare is to be maximised. At its best, telecare forms part of an individual ('personalised') package of care and support. To achieve this, individual needs must be identified and telecare then considered as part of the potential personalised response.

General and specialist assessment of need

Throughout the United Kingdom, community care needs assessment is now conceived of as a multidisciplinary process^{8 9 10 11}. In Scotland, much work has been done to encourage the use of 'shared assessments'¹² which gather core data on each individual (such as their name, age and ethnic group) along with information on physical, psychological, spiritual, and physiological needs. The process involves skilled interviewing to elicit what the person's needs are, and what their perception of those needs is at that time. There is an opportunity for a relative or close friend who is a carer to contribute – with the permission of the person. The assessment concludes with a summary of needs, followed by proposals for meeting them immediately (where necessary) and/or as part of a planned programme of care. (This will be dependent on resources being available and on eligibility criteria.)

The possibility of utilising telecare should be introduced during the assessment phase. Just as the person's need for home care, aids or adaptation, counselling or day services is considered, questions in the assessment form ought to trigger a discussion of telecare.

A good assessment of physical health is particularly important for a person with dementia. This will ensure that factors such as infections, changes in medication, or untreated physical pain are not being overlooked. Delirium is the term used to describe a range of symptoms of confusion that people with dementia are susceptible to if underlying physical conditions are not treated effectively¹³. Addressing these first will ensure that any decision to introduce telecare is based on a thorough and appropriate assessment of need. During the assessment itself, it is essential to explain what telecare is, using language the person will understand and can relate to. One approach is to start with the (universally familiar) community alarm service, then move to a general discussion of environmental monitoring equipment (flood and smoke detectors for example), before moving on to personal safety and health monitors, where appropriate. At this stage the assessor will be considering the potential contribution of telecare in general terms, as well as introducing the concept to the person and their carer(s).

In some areas, a 'core package' is offered to anyone with community care needs. This might consist of a community alarm and smoke and flood detectors, along with a security device for the front door. Increasingly, in new or refurbished supported or sheltered housing schemes, such equipment is installed routinely.

At its best, telecare forms part of a personalised package of care and support.

Opinion is divided on whether such an approach is cost-effective or not. Be that as it may, it does not obviate the need for individual needs assessments which will ensure that any additional equipment will meet identified needs.

All assessment documentation should therefore include a section prompting the assessor to consider telecare as part of the total response. It is also important that the assessor has access to information leaflets detailing the range of telecare that is available locally, what it is for and who is eligible – along with any costs which need to be met by the service user.

If the assessor believes that telecare can form part of the response and the person agrees, a more detailed assessment is then required. This should include the precise combination of devices which can best meet (in combination with other services) the person's needs, as well as clarifying issues around installation and response. This stage is often referred to as the 'specialist assessment'.

Specialist assessments

This secondary assessment stage is designed to personalise the provision of telecare by identifying items of equipment that appear to best meet the person's needs. At this stage additional factors – such as the design of the property and the availability of telephone lines, wireless networks and mobile phone signals – will need to be considered. The person's familiarity with electronic equipment will also be taken into account, along with any other telecare equipment already installed. In addition, their routine (for example when they like to go to bed and their sleeping pattern) will also be recorded to ensure that the equipment supports the lifestyle and degree of independence they want. Finally, the integration of the equipment with the rest of the support package, and the need for and availability of a response, will all have to be detailed.

There is no 'best' way of carrying out a specialist assessment. How it is carried out, and by whom, is likely to depend on local arrangements. In some areas, a telecare 'champion' will have been identified within the community care team. This person will have received additional training in telecare and regular updates on the range of equipment available. One of their responsibilities will be to undertake this specialist stage of the assessment, or perhaps to supervise and guide other team staff when such an assessment is needed.

In other areas this task is carried out by a dedicated telecare service. This group will include staff who carry out the call handling, monitoring and installation functions, and they will have links to any response service. The manager of the service, or a designated person, will be asked to take forward the specialist assessment and carry out any installation that is necessary.

Risk assessment

Risk assessment is a critical component of a good needs assessment. It takes into account the degree of risk experienced by the person, thereby identifying ways in which telecare can assist in the management of risk (by the person themselves, as well as by services). It includes risks in the home as well as outside. These may include risks:

- of fire if the cooker is left on
- of flood if the bathwater is left running
- of scalding in over-hot bathwater

Shared assessments gather core data, such as the person's name, age and ethnic group, along with information on physical, psychological, spiritual, and physiological needs.

- of unwelcome visitors
- of getting lost
- of harassment or hate crime

The most basic equipment, such as flood, smoke and carbon monoxide detectors, reduces risk in obvious ways. For people with cognitive impairments (for example arising from brain injury) and some sensory impairments, going outside and travelling can be particularly risky. If the nature of such risks is identified, then appropriate equipment can be selected. This process is illustrated in later sections of the book.

While telecare can be important in the management of risk, it cannot eliminate risk completely. No equipment yet devised is 100 per cent reliable. Routine testing and maintenance (for instance battery changes) are essential to maximise reliability. Even so, malfunctions can occur. Service users – or more often their friends, children or grandchildren! – may inadvertently trigger or disable alarms, and monitoring centres will not always be aware of this. So it is important to allow for reliability and human error in any risk management plan.

Using telecare to enhance assessment

Some companies have developed equipment which can log detailed information about a person's movement, lifestyle and routines within their home. This is used for needs and risk assessment purposes, as distinct from safety. An example is 'Just Checking'¹⁴, a portable activity-monitoring system designed for people with dementia (although not necessarily limited to that group). Small wireless movement sensors are triggered as the person moves around their home. These generate an activity chart which can be accessed via a secure website. This very detailed timed data can provide a much more accurate picture of a lifestyle than is possible from conversation with a person with cognitive impairment, or from carers who do not live on-site. Support, protection and care arrangements can then be targeted more accurately in a person-centred way.

Carers' assessment

In Scotland there is now a duty to offer informal carers an assessment of their needs arising from their caring responsibilities. This focuses on how they can be helped to sustain their contribution to the care of a person in need¹⁵. Research has confirmed the extent to which telecare can reduce pressure on carers; support them in their caring role; increase peace of mind about the safety and wellbeing of the person they care for; and enable them to sleep better¹⁶. It follows that a good carers' assessment will include consideration of the potential of telecare to indirectly benefit carers by helping them continue to care.

Recent research confirms, however, that many carers are unaware of the availability of telecare. It cannot be assumed that carers – especially 'new' carers – will be aware of the possibilities telecare offers. Equally, carers will have their own anxieties, and perhaps guilt, about using technology. They may be concerned about its reliability or whether they will understand it and be able to make it work. These issues will be considered in more detail in later chapters of this book. At this point it is important to emphasise that information needs to be made available to carers, and that where a carer's views are sought at the needs assessment stage their perspective and needs should be included and recorded.¹⁷

Research confirms that many carers are unaware of the availability of telecare.

3: Principles, rights and ethics

The previous chapter described the importance of carrying out a careful needs and risk assessment before introducing telecare. However, while good assessment will ensure that the use of telecare is person-centred and needs-led, it will not necessarily answer the question of whether telecare is 'right' for an individual.

As an example, consider the needs of a person with Down's syndrome who is in the early stages of dementia. The assessment process may indicate that a GPS-enabled wristwatch could reduce the person's exposure to risk when she is away from home. It will enable her carers – and a control centre – to pinpoint her at any time so that they can organise help if she becomes lost or experiences harassment. But the device could also be used to restrict her freedom to go where she pleases, which is a fundamental human right. The telecare device could be perceived as a kind of electronic tag, and this has associations with surveillance and the criminal justice system. Seen in this light, the ethical questions associated with telecare are more sharply exposed.

It may be difficult to comprehensively establish the needs and risks of a person who could benefit from telecare, whether they have dementia, a brain injury, or significant sensory impairment. To carry out an effective assessment, a system like 'Just Checking'¹⁸ might be introduced to their home on a temporary basis. This will provide comprehensive data on the person's movements and routines, including eating, sleeping and toileting. Although the resulting assessment will be very well-informed, this does not necessarily justify the invasion of privacy that is also involved. Similar dilemmas arise with the use of systems such as Betavista which allow control centre operators to see the person in their own home (albeit when an alert is triggered), as well as talk to them on a phone line.

Ethical dilemmas such as these should be considered using the case studies featured later in this book. The purpose of this chapter is to briefly describe an ethical approach to telecare, summarise some principles which need to be considered when decisions are being made, look at the relevant legislation and provide some hints for practice.

It is important to stress four things at the outset:

- each person's needs, choices and beliefs must be a fundamental consideration in any decision
- there are few absolute 'rights and wrongs' which can be universally applied to every situation
- ethical issues are not unique to telecare. Indeed, the principles, values and legal obligations discussed here apply to other care and support settings
- no one acts in a value-free or value-neutral way – we all have our value positions. The important issue is understanding these, articulating them as necessary (particularly to service users and carers) and

This chapter describes an ethical approach to telecare and includes an overview of the relevant legislation and some hints for practice.

understanding and thinking through any conflict that may emerge with the values of others, particularly service users and carers

Personal value systems

We all take up value positions and have opinions on issues like the smoking ban, how children should be disciplined and capital punishment. Some people consider these issues to be 'common sense' or 'obvious', but in practice they are complex. Our personal values are influenced by the way we were brought up, our education, the apparent values of our community and by our life experiences. For those working in care and support services, there are also our professional values. These are often expressed through codes of practice¹⁹ and feature prominently in our professional education at every level. As a result we learn – and try to integrate into our practice – core values such as a commitment to confidentiality, treating people with respect, maintaining dignity and individuality, and challenging racism, discrimination and injustice.

It is important that practitioners are aware of these values, and how they come to be part of their own value system. It is also important to appreciate that they may not always be shared by individual service users and carers, with the resultant need to resolve conflicts that arise from different value positions.

Principles

Some writers have developed statements of principles, or ethical theories, which can help ensure that the use of telecare is ethically sound. For example, Bjørneby et al (1999)²⁰ have proposed these principles:

- **autonomy** – people should be able to decide what they want to happen or be done to them
- **beneficence** – we should try to do good to the people we care for
- **non-maleficence** – we should try to avoid doing people harm
- **justice** – people should be treated fairly and equally

In addition to these principles, Bjørneby suggests that the perspectives and views of all those involved in the service should be sought in relation to both its implementation and the likely impact of its non-implementation.

Kemshall and Pritchard (1997)²¹ highlight the values and rights which they believe underpin community health and social care services. These include:

- a commitment to ensuring that all users and carers enjoy the same rights of citizenship as everyone else in the community, with equal access to service provision, irrespective of gender, race or disability
- a respect for the independence of individuals and their right to self-determination, including taking risks, and minimising any restraint on that freedom of action
- a regard for the privacy of the individual, intruding no more than necessary to achieve the agreed purpose
- respect for the dignity and individuality of every user and carer
- to maximise individual choice in the type of services on offer and the way in which those services are delivered

When making decisions about telecare, maintaining respect for the independence of individuals and their right to self-determination – including taking risks – is essential.

- a responsibility to provide services in a way that promotes the realisation of an individual's aspirations and abilities in all aspects of daily life

Cox et al (1998)²² describe a set of core values that should be incorporated into any person-centred service designed for someone with dementia:

- that the person using the service should have maximum control
- that real and informed choice should be a key part of any service
- that people who use services should be valued and respected as unique individuals
- that continuity of care is built into service delivery in a way that keeps the person in touch with their past and present
- that the person is not discriminated against on the basis that they have dementia or because of any other differences, and that they receive their fair share of good quality and appropriate services

These values and principles provide the basis for rules of practice that will ensure an ethical approach.

The law

In Scotland, three important Acts of Parliament have been passed since 2000: the Adults with Incapacity (Scotland) Act 2000; the Mental Health (Care and Treatment) (Scotland) Act 2003; and the Adult Support and Protection (Scotland) Act 2007²³. In addition to sharing a common purpose of protecting the rights of vulnerable people, these uphold a common set of principles: that any intervention must be intended to provide a benefit to the person which could not be reasonably obtained without that intervention AND that this is the 'least restrictive' option available. All three Acts also include a requirement to consider the person's views, along with those of significant others, like carers and family. The Adults with Incapacity Act is particularly relevant to this book because of its focus on the rights of people with significantly impaired capacity to make decisions.

Capacity and consent

There will be many occasions when the introduction of telecare raises issues of capacity and consent. The assessment process may indicate the presence of significant risk that telecare (in conjunction with other services) has the potential to reduce. Despite this, the person may refuse the service or be reluctant to accept it. This might be because they disagree with the perception of the risk and/or want to retain the right to choose the way they live.

When working with people who may benefit from telecare but also lack sufficient capacity to make decisions about risk and quality of life, there may be justification for overruling these fundamental human rights. However, these are very significant judgements which should be made carefully and legally. It may transpire that a person's capacity is not impaired after all, but instead their means of communication, or ability to communicate, has not been properly considered. This is generally apparent when the person has a hearing or speech impairment, or perhaps has had a stroke, but may be less obvious when the person has dementia.

There will be many occasions when the introduction of telecare raises issues of capacity and consent.

Where decisions are made on behalf of an individual who lacks the capacity to make choices for themselves, the course of action should be time-limited, regularly reviewed and limited to the particular services and decisions under consideration. Such decisions should never be considered as final or permanent.

Policy and procedures

Individual agencies will have policies, procedures and guidelines in place which ensure that staff remain within the law when delivering services – including telecare services. Implicit in these are the values of the agency, and of the community that it seeks to serve. For instance there will be commitments to equal opportunity, privacy, dignity and confidentiality, alongside procedural commitments to legality, cost-effectiveness and quality.

It is vital that practitioners are aware of these procedures and follow them. In the context of this chapter, practitioners should also be alert to conflicts between the values of users and carers and the values of their agency. These issues are often encountered in the area of risk and personal safety. Agencies have a duty of care, and in some cases their policies and procedures may conflict with the aspirations or expectations of the user, or their carer. For instance, procedures may prioritise the reduction of risk, as distinct from the freedom of someone to take risks and to make their own decisions. Practitioners need to be alert to these conflicts, and to make them explicit to users, carers and their own agency management. They must also ensure that the resolution of the conflict is recorded accurately and transparently.

Practitioners need to be alert to conflicts between the values of users and carers and the values of their agency.

Practice guidance

In summary, the following guidance is suggested:

- be aware of your own personal and professional value systems – and how these might conflict with the person you are working with and their carers
- be aware of the procedures of your agency, particularly those which are designed to protect the person's right to choose, to dignity, to privacy and to confidentiality
- ascertain as fully as possible the views of the person, their carers and other staff working with them. Do you understand what they are saying to you?
- are there issues of capacity to consent? If so, what are the legal issues around overriding their right to choice and consent?
- in what ways might the telecare solution limit this person's freedoms and rights? Is there an alternative which does not challenge their right to choose?
- how are the decisions to be made recorded? Has a record been provided to everyone who should have one? When is the decision to be reviewed?

4: Telecare and dementia

This chapter examines the value of telecare for people who have dementia, along with the potential for its use. An understanding of what dementia is and how it affects individuals is given first, followed by specific case studies.

Definition

Dementia is an umbrella term used to describe a number of progressive disorders that affect the brain. It is experienced in different ways depending on the specific type of dementia diagnosed and on an individual's past experiences. The most commonly associated features of dementia include memory impairment – especially short-term memory – and a decline in daily functioning affecting home life, work and leisure. The main forms of dementia are:

Alzheimer's disease. This is the most common form of dementia and is characterised by a gradual but persistent decline in cognitive functioning.

Vascular dementia. Here, a stepped progressive decline is noted with each decline often following a small stroke. Forms of vascular dementia include multi-infarct dementia and Binswanger's disease.

Dementia with Lewy bodies is characterised by hallucinations, widely fluctuating abilities, faints or falls and can be accompanied by symptoms of Parkinson's disease, such as muscle stiffness or tremors. Dementia with Lewy bodies does not respond well to antipsychotic medication.

Frontal lobe dementia affects the part of the brain that controls mood and behaviour. It can lead to aggression, inappropriate behaviour or lack of inhibition. Alternatively, withdrawal can be experienced. Forms of frontal lobe dementia include Pick's disease and motor neuron disease. Although rarer than other forms of dementia, it can occur more often in younger people.

Other forms of dementia include Huntington's disease; alcohol-related brain damage such as Wernicke-Korsakoff syndrome; Creutzfeldt-Jakob disease (CJD); and HIV- and AIDS-related dementia.

An accurate diagnosis is crucial to the support and intervention provided, although this is made more complicated because it is possible to have more than one form of dementia at the same time.

Incidence

Currently 700,000 people in the UK are estimated to be living with dementia;

Dementia is an umbrella term used to describe a number of progressive disorders that affect the brain.

around 66,000 of them in Scotland. Across the UK, people under the age of 65 make up at least 15,000 of this population.

The number of people with dementia will continue to rise due to the UK's ageing population. Estimates suggest that the total will exceed a million by 2025, costing around £17 billion annually (Alzheimer's Society, 2007)²⁴. Existing figures for the number of people with dementia are likely to be underestimates as they are based only on referrals to services.

Alzheimer's disease is not as common among younger people with dementia, but levels of frontal lobe dementia, dementia with Lewy bodies and alcohol-related brain damage are higher. The incidence of dementia among younger people with Down's syndrome is also particularly high (Kerr, 2008)²⁵. As many services for people with dementia cater for those who are 65 or over, they are not available to younger people. Where services are available, they are often not age appropriate, leading to a lack of resources and gaps in support for younger people with dementia that telecare could help address in certain circumstances.

Around two thirds of people with dementia live in the community, often with a spouse or family member as their main carer. This can result in significant emotional and financial strain for the carer. A smaller number of people live in care homes, although they form the majority of residents in these settings. People with dementia take up between a third and half of all long-stay hospital beds in geriatric wards. With these statistics in mind, it is important to consider how technology can enable people with dementia to remain at home if this is their preference. This approach has the potential to reduce healthcare costs while supporting the person and their main carer at the same time.

Telecare for people with dementia

A range of telecare devices is available to support people with dementia. However, each product must be evaluated to ascertain its suitability for a particular individual. Some devices are less likely to be suitable than others. For instance, those that makes a noise may startle or confuse someone with dementia. Knowing the person, their background and life story will help inform the evaluation process. Telecare has to be considered from the viewpoint of the person using it. For example:

- could an alarm be mistaken for a siren? The person may have lived through a war situation and become afraid
- does the person have any history of auditory hallucinations? This can occur with dementia and may be made worse by equipment that incorporates voice prompts

A life story book²⁶ can help inform decisions about the suitability of telecare equipment. It has the potential to enhance the assessment and decision-making process by providing information about the person and their life experiences. Life story work increasingly uses IT as the interface for producing materials. For example, the Scottish Government, in association with the Dementia Services Development Centre, has funded a system whereby life story books are designed online and a printed book is then produced from the photographs and other information uploaded. This service is currently free for people in Scotland with memory issues and can be accessed via the Caring Memories²⁷ website.

Around two thirds of people with dementia live in the community, often with a spouse or family member as their main carer.

Types of telecare

The **community alarm service** allows people to call for help when they need it by pressing a push-button pendant **1**, usually worn around their neck. The pendant sends an automatic message to a call centre, allowing the operator to identify the person, converse with them, and arrange support or call the emergency services if needed. The community alarm system can also be linked to medical devices such as blood pressure monitors, triggering alerts if a medical problem is detected. The call centre operator can then directly notify the relevant health professional, who will provide the support the person requires.

Enuresis sensors **2** alert carers or support staff when someone has had an episode of incontinence. The responder may be able to identify patterns of incontinence, potentially allowing them to predict and pre-empt incontinence by visiting earlier and assisting the person to use the toilet. Preventing incontinence promotes good skin care, and perhaps most importantly preserves the dignity of the individual requiring support.

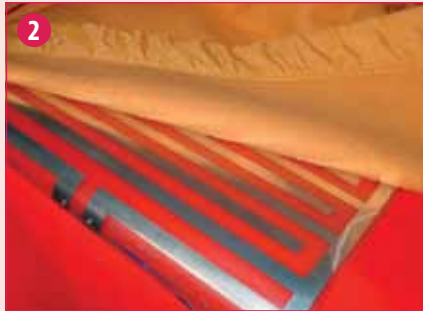
Door contacts **3** or **passive infrared beams** **4** can alert carers that the person has gone outside. This may identify an immediate risk, and can also help identify patterns indicating the best times to provide support. The data these devices provide may also help determine why the person is leaving the house at a particular time, contributing useful information to the assessment process.

Electronic location devices are another means of letting carers know when the person has left a room or building. They are used in conjunction with appropriately placed sensors, usually at doorways. In environments such as care homes, they can be given to those residents who are more likely to pose a risk to themselves on going outside, without sounding an alarm when other residents leave the building, for instance to walk in the garden. Some forms of location device combine **mobile phone** and **GPS** **5** **6** (global positioning system) technology and can be used to locate a person with dementia who may have left their home and become lost or disorientated. Providing the person remembers to wear the device or take it with them, their location can be accurately established. Some forms of these devices can be combined with a computer-based map to establish a safe area where the person with dementia is less likely to get lost. If they move outside this area, an alarm can be triggered.

Temperature **7**, **smoke** **8** and **carbon monoxide detectors** **9** detect dangerous levels of heat/cold, smoke or carbon monoxide in the room where they are placed. They can be linked with a number of devices, enabling gas or electricity supplies to be shut off automatically, or power-operated windows to be opened. Additionally or alternatively, when they are triggered they can alert a call centre.

Flood detectors **10** **11** **12** are activated when the floor becomes wet. They can be very useful if a flood may mean that the house will become uninhabitable for a period. This is because even a short admission to a care home while repairs are carried out could mean that the person with dementia is unable to return home due to the confusion experienced and disruption to their routine. Flood detectors can be over-sensitive and may be triggered by a minimal amount of water.

The number of people with dementia will continue to rise due to the UK's ageing population. Estimates suggest that the total will exceed a million by 2025.



Devices to stop sinks and baths overflowing. Magiplug **13** is a bath and sink safety plug that works using a pressure activated system. When an unattended bath reaches a certain depth the pressure plate opens and releases the excess water safely down the plughole, preventing flooding. This level will be maintained until the taps are turned off. When the desired level is reached the pressure plate will close again leaving you with a filled bath.

Medication reminders **14 15 16** use an alarm as a prompt and can help ensure that medication is taken at the same time every day. Some types are incorporated into a wrist watch. It is important that the person is not frightened or upset by the sudden noise when the alarm goes off, and if the reminder device is in their house, they need to be at home when it is activated in order for it to be effective.

Fall detectors **5 17 18** can be attached to clothing and are activated if the person falls. In order to be effective they must be worn at all times.

Case studies

When reading the following case studies, it is important to bear in mind that telecare should not be considered or introduced in isolation. Instead, it should form part of an agreed and planned package of care. As dementia is progressive, the type of care and support provided will need to be assessed and revised on an ongoing basis.

Case study 1

Mrs MacAndrew is 80 and lives alone following the death of her husband. He had managed most of the daily household activities such as cleaning, shopping and cooking. Mrs MacAndrew recently had a fall in the garden and was found by a neighbour who helped her inside. The neighbour noticed that the house was untidy and that food in the fridge had gone off. She alerted social services, and an assessment of Mrs MacAndrew highlighted that she had dementia and that her husband had been providing a routine that meant she was previously able to manage well at home.

Following the assessment, a meeting was arranged with Mrs MacAndrew and her daughter, after which a telecare package was put in place alongside other support. Mrs MacAndrew's daughter agreed to visit twice weekly and to assist with shopping and food planning. She also recorded a message reminding her mother to prepare a planned meal, and this was programmed to automatically play at appropriate times. The recorded message was backed up by a written meal plan on the fridge. Mrs MacAndrew's daughter was able to monitor the success of this technology on each of her visits. Mrs MacAndrew was also given a pendant **1** linked to the community alarm service, which she started wearing around her neck. This meant that if she did fall she could seek assistance through a call centre.

Case study 2

Miss Anderson is 70 and increasingly confuses night and day. She becomes distressed at night when she is unable to find the toilet and has become incontinent.

Following an initial assessment, a number of changes were introduced to support Miss Anderson. Light bulbs were checked to ensure that they gave out enough light²⁸, enabling her to see clearly. Leaving the bathroom light on helped her to orientate herself at night, as did establishing a clear line of vision to the toilet from her bed. Miss Anderson also had a medical examination to check her vision and to ensure there were no treatable causes of incontinence, such as a urinary infection.

However, despite these changes Miss Anderson continued to have problems and complained about the light being left on at night, as she was concerned about the cost and was being kept awake by the light. With her permission, a passive infrared (PIR) detector **4** was then installed. This emits a harmless, invisible beam that can trigger a switch when broken by something passing across it. It has been set so that when Miss Anderson gets out of bed and interrupts the beam the bathroom light comes on. This has enabled her to find the toilet at night, but does not disturb her sleep.

Case study 3

Mr Ramsey is 80 and has Alzheimer's disease. He regularly leaves his home at night to try to go to work, and his family are increasingly concerned for his safety. Neighbours have also alerted social services about the need to make sure that he is kept safe.

Initially, a PIR linked to a light box **19** was used to help Mr Ramsey. This was fitted to the inside of his external door, and when he approached the door the beam was broken, illuminating a message on the box reading 'Don't go out as it is night time'. Using a time switch the light box was programmed by his home help to come on during the hours of darkness. The wording of the message was changed regularly (although the meaning stayed the same), to make sure that Mr Ramsey did not get so used to it that he stopped noticing it. The intervention has been successful, although if it had not worked other techniques could have been used. For instance, newer mobile phones incorporate global positioning system (GPS) tracking devices, which can be used to locate an individual. However, the system also depends on the person having the phone with them, as well as being switched on with the battery charged.



Case study 4

Mrs Adams was diagnosed with dementia with Lewy bodies at the age of 63. Her children live over 100 miles away and want her to move near to them, especially as she is forgetting to call at night to let them know she is OK. Mrs Adams wants to stay in her own home.

A meeting was arranged between Mrs Adams, her daughter and her care manager. During the meeting her daughter explained how her mother had previously phoned her at the same time each day, but because her memory was now so poor she often forgot to call. This was a cause of considerable anxiety for her daughter. It transpired that Mrs Adams was having problems reading the telephone number in her address book and seeing the buttons on her phone. She had been avoiding telling her family this in case they put more pressure on her to move.

Following the meeting, a sight test was arranged for Mrs Adams, and she was provided with a telephone with large pre-programmable picture buttons **20** featuring photographs of her family members. As a result, she no longer has to remember or read phone numbers, and instead can just press the button featuring the picture of the person she wants to call. Her family have also arranged for one of the buttons to be programmed to summon help if Mrs Adams has concerns about a stranger at the door.



Case study 5

Mr Elliot has become withdrawn and isolated since the death of his wife eight months earlier. He no longer goes to his bowling club, preferring to stay at home. He has forgotten to take his medication on occasion and his neighbour has seen him going out without a coat. His children and grandchildren are worried about his forgetfulness.

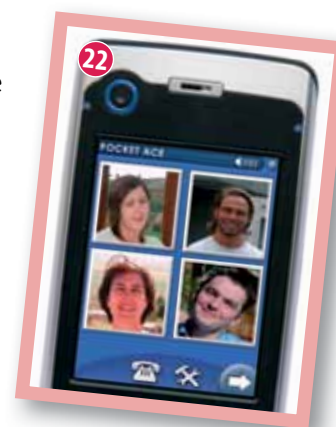
A balance needs to be struck between ensuring Mr Elliot's wellbeing and respecting his privacy. Firstly, the reasons for his withdrawal need to be understood: they may relate to fear or depression, rather than dementia. If he is diagnosed with dementia, it may transpire that his wife was previously able to compensate for the difficulties he was experiencing, which is why they are only now becoming apparent. Many of the issues Mr Elliot is experiencing can potentially be addressed using telecare. An automated dispenser could be used to store his medication and programmed to sound an audible alert when it was due to be taken. Depending on the specific areas in which Mr Elliot was becoming forgetful, prompts and reminders could be placed around the home. For example, a picture **21** of him wearing his outdoor coat could be placed on the back of the exit door. If necessary, these simple prompts could be supplemented with other devices such as pre-recorded verbal messages which are triggered as he opens the door.



Case study 6

Miss Ryan is 49 and has a learning disability and dementia. She travels to college three days a week and volunteers in a charity shop on Saturdays. Following her diagnosis with dementia, her parents have become worried about her continuing to travel independently and have discussed the possibility of her stopping attending college. Miss Ryan is very upset by this and is keen to maintain her routine and independence.

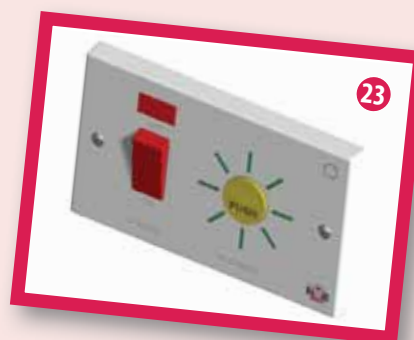
In view of these concerns, Miss Ryan has been given a mobile phone which uses pictures rather than numbers or names ²² so she can easily call her parents or support staff if she has any difficulties. The phone also has GPS functionality so her parents can locate her if they need to. Additional support at home has included using digital photographs to create a pictorial timetable for Miss Ryan.



Case study 7

Mrs Fraser has had dementia for six years and has remained at home with the support of her family. Recently she has been forgetting to turn the oven off and on one occasion a small fire started that had to be extinguished by a neighbour. The neighbours are now concerned for her and feel that she should be in care.

A number of devices have since been fitted to monitor and prevent the risk of fire. Smoke detectors have been fitted throughout the house and Mrs Fraser's home help has agreed to regularly check them. Additionally, a wireless heat detector has been fitted to provide additional security, particularly in the kitchen where a smoke detector may be too sensitive. As part of the assessment process it was noted that Mrs Fraser had recently started some new medication and this was reviewed to ensure it was not contributing to her bouts of forgetfulness. The assessment also indicated that Mrs Fraser would benefit from a newly developed cut-off timer ²³ linked to her hob. The types of meals prepared by Mrs Fraser only require the hob to be on for short periods so the timer could be fitted to turn off automatically after 20 minutes.



Understanding the person

Prior to any form of telecare being introduced, clear benefits must be established for the person with dementia. It is important to find a balance between ensuring safety and protecting privacy whilst being realistic about potential risks. Any intervention should be discussed with the person who has dementia and their family in a clear manner, with easily understood guidance notes left with the person both as prompts and to reaffirm consent to use the technology. Many options are available, and the most appropriate one may not be the most commonly used or widely known. In the USA, video monitoring has been used to ensure that patients with dementia were taking their medication appropriately²⁹.

Understanding the person with dementia and their life experiences is crucial to the implementation of telecare. This includes knowing how they communicate – for instance understanding the body language they use to express pain, pleasure or discomfort – and appreciating how their living environment impacts on them now, as well as how it did in the past. For example, a person who grew up with an outside toilet is unlikely to look behind a closed door for a bathroom. They may instead go outside when they need to use the toilet, and to discourage this the indoor toilet must be visible or clearly identified. In this example and others, there are a range of options available to support both the person with dementia and their carer. The solution may be as simple and low-tech as a pictorial sign on the bathroom door. In other cases, simple electronic or mechanical devices can make a big difference, such as a device that prevents the bath from becoming too full. This may be an audible electronic alarm, or if this will cause distress, a modified plug that automatically lets excess water flow away before the bath gets too full.

Simple solutions can provide a great sense of relief to family members and carers.

Consent

Consent is a very important issue to consider when using telecare to support someone with dementia. People with dementia may have difficulty understanding what is being proposed and the impact it will have on their lives. The assessor may also have difficulty in understanding the person. They need to know how the person with dementia communicates, and must ensure that they involve them in the decision-making process and that they have consulted with them and/or their representative. It is important that the principles set out in chapter 3 are applied, and that staff are appropriately trained in communicating with someone who has dementia.

Issues for carers

The benefits of electronic assistive technology are potentially significant for carers too. Simple solutions can provide a great sense of relief to family members and carers. With appropriate technological support, people can remain safe both in their own homes and outdoors. Technology can enable the person with dementia to enjoy higher levels of independence, with the result that they need less time and support from carers. Devices such as pagers and alarms mean that individuals can call on assistance more easily if required, and this provides a degree of security for relatives and carers. As a result, relationships are less likely to be strained.

However, there are still a number of hurdles to overcome before telecare can be deployed effectively. Firstly, carers may not be aware of the availability of telecare to support them in their caring role, or appreciate its potential. Secondly, it cannot be assumed that the carer of a person with dementia will be supportive of the use of technology – or that they will monitor its use. Likewise, carers may have concerns about adaptations to laptops, mobile phones and domestic equipment – perhaps because of inconvenience, anxiety about change, reliability or stigma.

Good planning at an early stage can avoid the need for crisis decisions being made. To be effective, telecare needs to be part of a long-term care package that is regularly reviewed and incorporates the needs of the person with dementia, along with those of their carer. For consistency, respite carers and

those offering short breaks need to be aware of any use of technology by the person. Implementing telecare effectively is likely to require clear explanations for carers, as well as for the person with dementia.

Carers and care staff also need appropriate training and support in the use of telecare. Although use of mobile phones and the internet is widespread, it should not be automatically assumed that staff or family members will be familiar with them. Staff may have no desire to use these technologies themselves, so may have difficulty incorporating them into their daily work. What may be seen as reluctance to support a person with dementia may in reality be due to feelings of uncertainty about the technology which need to be acknowledged. These issues can be overcome by support and training. In some cases the carer or staff-member may learn alongside the person with dementia, which can prove beneficial for both. Training and support for staff are essential, and should form part of personal development plans which will ensure that this area of work is recognised and acknowledged. Additionally, clear lines of accountability and reporting are needed. If necessary, job descriptions and person specifications should be expanded for both existing and new staff to reflect their expanded role.

It is important that more than one staff or family member is familiar with any technology that is introduced. There will normally need to be someone on shift at all times who is familiar with how each piece of equipment works. Equally, call centre staff need to be aware that the person they are responding to has dementia and understand the necessary communication and response arrangements. These should be in the individual response protocol that is established at the time of installation. Discussing this plan regularly at team meetings will mean that staff are familiar with the issues they may encounter, rather than becoming stressed when they face a problem or receive a call. This is especially important in organisations where there is a high staff turnover or regular use of agency staff.

When telecare is first introduced, paid staff may have concerns about their job security and be fearful of being replaced by technology. Although the introduction of telecare may open up possibilities for new or different roles, this need not be at the expense of contact time and social interaction with people who have dementia – especially those living alone, for whom loneliness can be a very real issue. Instead, routine ‘supervision’ or check visits can be replaced by equipment, freeing up staff time for more worthwhile social interaction.

Carers and care staff also need appropriate training and support in the use of telecare.

5: Training programme

This section contains content and a suggested timetable for a one-day training programme on how telecare can contribute to the care and support of people with dementia. It may also provide a basis for a longer programme for specialist assessors or 'telecare champions' if combined with 'shadowing' experiences and visits to a control centre, response team, and contact with service users already experienced in telecare. Similarly, it may be of value to course leaders of qualifying programmes for social workers, occupational therapists and community nurses.

It is an outline programme which skilled trainers will need to adapt to the particular training needs and circumstances of local groups.

Aim

To support participants in the development of the knowledge, skills and understanding required to introduce telecare into individualised care packages.

Objectives

- to learn how telecare can contribute to the support of people with dementia and their carers
- to develop practice in needs and risk assessment, and care planning, so as to maximise the benefits of telecare
- to increase knowledge of the legal and ethical framework for good practice
- to understand the wider policy and strategic context for telecare

Timetable

9.00 Welcome and introductions

- domestic arrangements
- discuss agenda and clarify expectations of the course. Refer to the aims and objectives to confirm what the course can and cannot provide. Invite participants to discuss, briefly, with each other, their current knowledge and understanding of telecare, their perceptions and anxieties about technology, their expectations of the day, and their individual training needs

9.30 Definitions of telecare and telehealth

This could be a 'teaching' session with a presentation and handout based on the definitions provided in the introduction to this book.

Key learning points are:

- the meaning of terms such as telecare, telehealth, telehealthcare and an introduction to the 'generations' of telecare
- the lack of commonly accepted standard definitions, and the extent to which terms are interchangeable, and changing
- the speed with which technology is developing in all areas of our lives
- the effect of this on service user and carer expectations

In this session it will also be important to remind participants about the nature and impact of different sorts of dementia, and so begin to explore the ways in which technology can support people with different presentations. Assuming that participants will already be working in the field of dementia, the key learning points will include:

- being aware that the successful introduction of telecare depends on understanding the individual nature of a person's dementia
- being able to develop and use specialist communication skills if the dementia has affected speech or comprehension
- taking a person-centred approach to care and support and encouraging higher expectations among the family and carers of the person who is being considered for telecare. This includes developing a proactive approach which engages the person in meaningful and enjoyable activities
- being open to new and changing ways of providing support

Gather together any thoughts and initial reactions at this stage without looking for conclusive ideas. Some of the definitions may be new to participants, and time is available to ask questions about these throughout the day. Reassure participants that they will have the opportunity to apply these to practice later.

10.00 Understanding dementia

Discuss:

- what dementia means and the different forms that it can take
- the impact on people at an individual level including employment, leisure, family life, relationships and identity
- non-technological interventions in dementia care: highlight the role of meaningful activities, understanding reality, life story, reminiscence and music

Stress the need to understand the unique experience and impact of dementia for each individual.

10.30 How can telecare help support people with dementia?

This should be an opportunity for participants to see pictures of, and, if possible, actually touch and feel equipment. It is important to explain the kind of support needs for which pieces of equipment may be useful, and to talk through examples of equipment which may be in development but not yet available.

Local providers and suppliers may offer to put on a display of equipment, at no charge. If there is a local 'smart house' it may be possible to locate the training session there – or to organise a visit at the end of the day or at the lunch break.

Ask the group to look at the illustrations of equipment and share their ideas about each item's uses and limitations. Participants may have additional valid suggestions about uses and limitations based on their own experiences. Ask the group to split into pairs and think about a person they know who may benefit from some of these adaptations or interventions, along with someone who would be unlikely to benefit from them.

11.00 Break

11.30 Case studies – telecare in practice

In this session, participants will look at a variety of different scenarios in pairs and think about how the equipment or intervention suggested may or may not be useful. Group-members should consider whether any other interventions may be relevant and think about wider issues relating to care, for example the implications of different types of dementia:

- what is the need that is to be met (the importance of careful assessment; avoiding simplistic solutions; not 'just giving out bits of kit')
- the different perspectives of the service user, their family and support staff
- how the age of the person with dementia is relevant
- how their background and previous experience are relevant
- what impact there could be on persons with different types of dementia
- differing attitudes to risk
- how telecare can supplement other kinds of support but is not intended to replace them
- the importance of maximising levels of independence and retaining personal skills
- promoting proactive self-management of long-term health conditions or disabilities
- encouraging/enabling individuals to remain in their own homes/communities for as long as is safely possible
- reducing unnecessary movement to alternative forms of accommodation, such as nursing homes, care homes and hospitals
- fostering a feeling of security for individuals and their families
- improving quality of life
- providing greater choice

Ideally, participants will share their own experience and 'cases' with colleagues and expand the case studies to create different potential scenarios. Advise that

there are not any right or wrong answers and that the exercise will highlight the individual nature of dementia, along with the importance of ongoing communication to determine the person's wishes and preferences.

12.30 The importance of good assessment

Bring participants back together as a single group and compare the ideas that emerged in the previous session. Encourage debate about how telecare contributed to the support of the individuals in the case studies in the following ways:

- draw out the importance of good assessment. Refer to the section on assessment in this book. If necessary, develop a handout or use an example of a local assessment tool
- make sure risk is considered, as well as need
- highlight the differing concerns and benefits as seen from different points of view
- bring any difficult issues into the open, such as staff reluctance or how carer concerns should be addressed
- highlight what the problem is and who the telecare is intended for. Are there consent issues, or differing perspectives on risk, need, capacity or consent?

13.15 Lunch

14.15 Telecare may be the solution ... but is it 'right'?

This is an opportunity to discuss with participants the rights and wrongs of using telecare, looked at from their own perspective, as well as their employer's and professional perspectives. Chapters 2 (Assessment) and 3 (Principles, rights and ethics) may provide the basis for a short introductory talk. Alternatively, this could be an interactive session in which the following kinds of questions are posed:

- telecare can involve the monitoring of people's private lives. Is that 'right'?
- some equipment restricts people's freedom to do as they want or go where they want in order to 'protect' them. What is the right balance between risk and protection and how do we achieve it?
- telecare can be used to support a 'normal' lifestyle – getting up in the morning, going out during the day and going to bed at night. Is telecare being used to 'impose' a conventional lifestyle?

Stress that people with dementia should only have their movement restricted or monitored with permission, and where this complies with the law and care regulations. Discuss what permission means where there is significant cognitive impairment and talk through what the law dictates in this area. These issues can be discussed in the context of the case studies from the previous session.

Participants need to be clear about the legal constraints on this (and any other) part of their support service. They have a responsibility to make decisions that are both ethically defensible and legal. An approach based on individual assessed needs will always present ethical dilemmas which need to be resolved.

15.00 Policies, procedures, and strategy to support the use of telecare

This session provides an opportunity for participants to explore and gain a better understanding of local policy and procedures. It should include discussion of local assessment tools to ensure that participants understand when and how telecare can be introduced into the assessment process. Local procedures for accessing telecare, as well as for installation, testing and responding to call-outs, should be discussed and explained, along with charging policies and budgets.

It may also be useful to discuss local strategy. How does the use of telecare fit with local joint strategies for people with dementia? If time is available, it will be useful to look at the national strategy too and discuss how telecare can contribute to national policy goals such as Shifting the Balance of Care. (Resources are available on the National Telecare Development Programme website – www.jitscotland.org.uk/action-areas/telecare-in-scotland/)

16.15 Conclusions and evaluation

Summarise and ask what the participants will take away from the day. The discussion could include areas of new technology and the potential for the future use of telecare and telehealth as a way of supporting people with dementia.

Additional resources*

For further information about telecare and the National Development Programme in Scotland, please contact the Joint Improvement Team via their website:

<http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

The website for the equivalent programme in England is:

<http://www.dhcarenetworks.org.uk/independentlivingchoices/telecare/>

Other websites

Information and general advice from the Disabled Living Foundation:

<http://www.livingmadeeasy.org.uk/telecare-167/>

Consumer reports on telecare equipment:

http://www.ricability.org.uk/consumer_reports/at_home/

Home Farm Trust is a national charity supporting people with learning disabilities and their families. For more information about what they call 'personalised technology' email personalisedtechnology@hft.org.uk or visit http://www.hft.org.uk/What_we_do/Assistive_technology

The AT Dementia website brings together information about assistive technology that has the potential to support the independence and leisure opportunities of people with dementia: <http://www.atdementia.org.uk/>

Information on assistive technology for people with dementia:

<http://www.atdementia.org.uk>

Telecare Services Association (TSA):

<http://www.telecare.org.uk>

Social Care Institute for Excellence – Dementia Gateway. This section of the website looks at the use of technology:

<http://www.scie.org.uk/publications/dementia/environment/assistive.asp>

Centre for Usable Home Technology:

<http://www.cuhtec.org.uk/>

Centre for Accessible Environments:

<http://www.cae.org.uk/>

Enable:

<http://www.enableproject.org/>

Dementia Services Development Centre:

<http://www.dementia.stir.ac.uk>

DVDs

Telecare – supporting Scotland: a different approach. DVD which includes seven 'digital stories' illustrating, in the words of users and carers, the impact of telecare. Available through

<http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>

Telehealth in Action. Scottish Centre for Telehealth:

<http://www.sct.scot.nhs.uk>

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Supplier contact details

The images of equipment featured in this book represent a small subsection of the range currently available. The contact details below have been included to assist purchasers in assessing what is available from whom, but in many cases the same device is available from more than one supplier. The publishers in no way endorse any particular supplier or product. The lack of inclusion of a particular product does not imply that it is inferior to any device featured. Purchasers are responsible for researching the full range of products available and reaching their own conclusions about what is most suitable for them or their clients.

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